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BMJ Open Outcomes valued by people living with dementia and their care partners: protocol for a qualitative systematic review and synthesis

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ABSTRACT

Introduction Growing numbers of interventions are being developed to support people and families living with dementia, but the extent to which they address the areas of most importance to the intended recipients is unclear. This qualitative review will synthesise outcomes identified as important from the perspectives of people living with dementia and their care partners, both for themselves and each other.

Methods and analysis The review will employ thematic synthesis methodology. Studies from 1990 or later will be eligible if they include qualitative data on the views of people living with dementia or their care partners on valued outcomes or the lived experience of dementia. Databases to be searched include MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycInfo and Social Sciences Premium Collection, in addition to systematically gathered grey literature. Rayyan QCRI software will be used to manage the screening processes, and NVivo software will be used to manage data extraction and analysis. The review will also critically evaluate the extent to which international recommendations address the areas of importance to people living with dementia and their families. The findings will be of relevance to researchers, policy makers and providers and commissioners of dementia services. The protocol is written in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols guidelines.

Ethics and dissemination As the methodology of this study consists of collecting data from publicly available articles, it does not require ethical approval. We will share the results through conference presentations and an open-access publication in a peer-reviewed journal. Our mixed stakeholder involvement group will advise on dissemination to non-academic audiences.

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INTRODUCTION

International policy is undergoing a shift in focus from improving diagnostic rates of dementia to enhancing postdiagnostic support, reflected in an emphasis on enabling people to 'live well' with dementia^{1–7} or to live a life with meaning and dignity.⁸ To

Strengths and limitations of this study

- We will focus on outcomes articulated by people living with dementia and care partners using qualitative methodologies.
- We will include studies of the lived experience of dementia, which are likely to highlight important outcomes but have not been included in previous reviews.
- Outcomes valued by people living with dementia and care partners will be explored and compared.
- The perspectives of people living with dementia and their care partners have informed our study design and will contribute to data interpretation and dissemination through lay involvement.
- Studies not published in English will not be included in this review but will be labelled and recorded.

achieve these emerging policy aims, we need to understand what these abstract concepts, along with similar concepts such as 'needs', 'quality of life' or 'well-being', mean to people living with dementia and their care partners, caregivers or carers (hereafter, care partners) in order to translate them into specific outcomes, which can be used to inform and evaluate postdiagnostic support. It is essential to involve people living with dementia and their care partners in this process of translation to ensure that interventions focus on the outcomes valued by the intended beneficiaries,⁹ as highlighted in the Organisation for Economic Co-operation and Development (OECD) call for health systems to 'measure what matters'.¹⁰

The term 'outcome' may be used in different ways. The UK National Health Service Good Indicators Guide defines outcomes as 'a measurable change in health status, sometimes attributable to a risk factor or an intervention'.¹¹ This definition is strongly focused on changes in health, which

can be problematic when applied a condition such as dementia that also has substantial emotional and social components¹²; Coulter¹⁰ has argued that outcomes for people living with long-term conditions, such as dementia, should encompass a broad view of health and well-being, rather than focusing on physical functioning. Nocon and Qureshi¹³ have defined outcomes more broadly as ‘the impact, effect or consequence of a service or a policy for service users’, while Harding *et al*¹⁴ have defined outcomes as ‘the impact of activity or support and services’. In this review, we are using an amalgamated definition: ‘the impact, effect or consequence of activity, support, services or policy for people living with dementia and/or their care partners’. By adopting this broad definition, we hope to identify outcomes that may have otherwise been missed.

Recent research into outcomes prioritised by people living with dementia and care partners has focused on developing core outcome sets for intervention studies. To date, core outcome sets have been developed for disease modification trials,¹⁵ psychosocial interventions,¹⁶ physical activity,¹⁷ medication management¹⁸ and non-pharmacological community-based health and social care interventions.¹⁹ Such core outcome sets developed for use in specific contexts may have limited utility when evaluating the impact of interventions, services and national policy, which may have broader aims and seek to address multiple areas. Furthermore, the extent to which the views of people living with dementia have been included in these studies varies, although some have developed innovative methods to capture their perspectives.^{18 19} This has sometimes highlighted discrepancies between outcomes valued by people living with dementia and those valued by professionals.^{17 18}

A recent systematic review sought to address the above limitations by focusing on outcomes important to all key stakeholder groups: people living with dementia, their care partners and healthcare professionals. It described 32 outcomes grouped into categories of clinical, practical and personal.²⁰ However, the study focused only on Alzheimer’s disease and mild cognitive impairment.²⁰ A review of qualitative and mixed-method studies found a very wide range of needs of people living with dementia and care partners including physical and mental health, social activities, information provision and financial assistance.²¹ However, some studies in the review relied on prespecified lists of needs²¹; all needs may therefore not have been captured. Recent systematic reviews focusing on outcomes for carers,^{22 23} including children of parents with young-onset dementia,²⁴ have been conducted. However, these studies were limited in scope as they did not incorporate grey literature. Other issues include not exploring the relationship between needs for the care partner and needs for the person with dementia²³; a systematic review on mutual support between patients and care partners²⁵ did not incorporate any studies about dementia, suggesting this is an under-researched area. Moreover, we identified a conceptual muddle around

interpreting outcomes that people living with dementia/care partners value for themselves versus outcomes they value for the other person.^{20–22} In addition, the majority of studies included in recent reviews of outcomes^{20–24} and lived experience^{26–30} have been from higher-income countries; there is therefore a need to explore the views of people living with dementia and their care partners in lower-middle-income countries as these may differ.

In order to comprehensively describe outcomes valued by people living with dementia and their care partners, this qualitative synthesis aims to build on existing literature by systematically reviewing relevant databases (research, grey literature and policy) for papers exploring the related concepts of outcomes, needs, well-being and quality of life. Papers on the lived experience of dementia will also be incorporated; while previous reviews have explored lived experience separately^{26–29} and incorporated it into measures of well-being,³¹ these studies have not previously been used to inform outcomes. As articulating outcomes can be challenging, particularly if there is a focus on outcomes of specific services, where people living with dementia and care partners may have low expectations or be unaware of the wider range of outcomes that could be achieved from a comprehensive package of support, we believe these studies will shed additional light on valued aspects of life, which may otherwise be missed. Finally, we will add to the existing literature by explicitly exploring the outcomes valued by people living with dementia for their care partners and vice versa in addition to the outcomes that each value for themselves; in previous syntheses, these four strands have frequently not been adequately separated.

METHODS AND ANALYSIS

Protocol and registration

The protocol is registered with PROSPERO and is reported in line with the Preferred Reporting Items for Systematic Review and Meta-Analyses Protocols (online supplemental file 2).³²

Search strategy

We identified three domains of interest relating to the research question: type of study, participants and the phenomena of interest (ie, outcomes or lived experience). For each domain, we identified relevant keywords or search terms, drawing on published search strategies with the addition of search terms, keywords and text words in the titles and abstracts of papers identified in pilot searches (see table 1). The search terms were used to develop tailored search strategies for each information source (see Appendix 1 (online supplemental file 1) for the MEDLINE search); an information specialist reviewed the proposed search terms. Since not all databases will be able to accommodate the full set of search terms, the strategy will be modified as appropriate. Details of the specific search terms used for each information source will be recorded.

Table 1 Terms and synonyms used to inform the search

Group	Terms		
1. Qualitative methodology	Interview Focus group Fieldwork Discussion	Ethnography Questionnaire Qualitative	Phenomenological Grounded theory Narrative
2. Dementia	Dementia Lewy body disease	Alzheimer's disease Frontotemporal degeneration	Frontotemporal disorder
3. Outcomes	Need Want Demand Domain Important	Well-being Quality of life Prefer Satisfaction Impact	View Outcome Hope Cope/coping Expect
4. Lived experience	Experience Meaning Perception Understanding Subjective	Everyday/daily life Narrative Perspective Scheme Existence	Representation Value Belief Identity Self

Types of study

We will focus on studies reporting original qualitative data since our aim is to synthesise outcomes articulated by people living with dementia and care partners. Publications have explored the relative merits of different approaches to identifying qualitative research in different databases.^{33–38} We will use the University of Texas School of Public Health³⁹ search for qualitative research, which was reported to have the best balance between sensitivity and precision.³³ To increase the accuracy of this strategy, we modified the search after examining known papers in the specific field of interest, adding terms for 'phenomenology', 'grounded theory' and 'narrative'.

Participants

Studies must include people living with dementia and/or their care partners. Although there are established search strategies for dementia (eg, those used to update evidence for the recent guidelines by the National Institute for Health and Care Excellence in England),⁴⁰ these were not considered appropriate for identifying qualitative studies. Instead, we will use a less complex strategy informed by terms used in previous reviews, supplementing the term 'dementia' with specific subtypes where these did not necessarily contain the word 'dementia' (eg, Lewy body disease). We will be more inclusive than previous reviews by not specifying place of residence or including terms relating specifically to service use.²¹

Specific search terms relating to care partners have not been included, as papers focusing on care partners for people with dementia are a subset of papers about dementia and will be retrieved by our existing search. Adding such terms would have additionally required us to operationalise the term 'care partners' to ensure that all relevant papers were included; this was an issue in previous reviews, which used a limited range of terms for care partners.^{20 21}

Phenomena of interest

We will identify papers describing the outcomes valued by people living with dementia or their care partners. We will use a broad range of search terms to capture papers exploring related concepts such as well-being and quality of life (see [table 1](#)); these terms were developed through iterative team discussions, previous reviews^{20 21} and examination of known papers of interest to ensure they were comprehensive. Additionally, papers describing lived experience of dementia may provide significant insights into areas of life that have particular salience or value to people living with dementia and care partners; we will therefore also include a range of terms relating to lived experience (see [table 1](#)), developed through a similar iterative process consulting previous reviews.^{26–29} Relevant studies need only describe either outcomes or lived experience, not both. Previous reviews have limited potential results by including a complex combination of search terms, for example, the requirement to include 'priorities'²⁰ or terms relating to evaluation²¹; in keeping with our broad definition of outcomes, we have used a more streamlined search strategy.

Data sources

Previous studies have recommended using a range of approaches to identify relevant information^{41 42}; sources to be used in the present study are summarised in [table 2](#).

We will adopt the following definition of grey literature: 'the diverse and heterogeneous body of material available outside, and not subject to, traditional academic peer-review processes'.⁴³ We will focus on first-tier grey literature (which has significant retrievability/credibility and typically includes books, book chapters, government reports and 'think tank' publications).⁴³ Since there is no 'gold standard' for searching the grey literature,⁴⁴ we have drawn on accounts of grey literature searching in published qualitative syntheses to identify the most appropriate sources for

Table 2 Data sources

Approach	Specific sources
Electronic databases of academic articles ³⁴	MEDLINE, CINAHL and PsycInfo Social Sciences Premium Collection (including IBSS and ASSIA)
Internet search engines ^{42 45}	Google Scholar
Citation pearl growing	Review of references and citations of included studies Related article searching Citation alerts Publications of authors of included studies
Databases of grey literature ^{41–43}	OpenGrey British Library Catalogue
Targeted websites of funders and third sector organisations ⁴⁰	Informed by the list of organisations included in grey literature searches by NICE ⁴⁰ (see Appendix 2 in online supplemental file 1)

ASSIA, Applied Social Sciences Index and Abstracts; CINAHL, Cumulative Index to Nursing and Allied Health Literature; IBSS, International Bibliography of the Social Sciences; NICE, National Institute for Health and Care Excellence.

this review.^{41 42 44 45} We started by considering the types of grey literature we wished to identify and then the sources from which these were likely to be retrieved, including international policy documents and reports by organisations for people living with dementia. UK think tanks were identified by Google searches and then rapidly reviewed to ascertain their potential relevance to our work. A detailed description of sources to be included in the grey literature search is provided in Appendix 2 (online supplemental file 1).

Data collection and analysis

Selection of studies

Details of the inclusion and exclusion criteria are provided in table 3.

Screening process

Titles and abstracts of all papers identified through searching will be reviewed by one researcher. Previous authors have highlighted inconsistencies between reviewers during screening.⁴⁶ To develop a collective understanding of how to operationalise the screening criteria, all researchers will screen a sample of 10 papers independently and then compare and discuss decisions. This will enable areas of ambiguity to be identified and resolved. This process will be repeated iteratively until the review team is confident in applying the criteria. Regular screening meetings will be held to discuss uncertainties and further clarify screening criteria as needed. Any papers where a decision cannot be reached by discussion will be included for full text review.

A similar process of comparing screening decisions on samples of full text papers will be used to maximise consistency in applying the screening criteria. A proportion of full

Table 3 Inclusion and exclusion criteria

Criteria	Justification
Conducted between 1990 and 2020	The earliest relevant paper identified in previous reviews was in 1992; we therefore propose to cover the last 30 years to ensure that we include all relevant publications.
Reports perspectives of people living with dementia or care partners	Participants are either people living with dementia (all subtypes) or their care partners. Evidence of formal diagnosis is not required for inclusion. We are using the term 'care partners' to mean family members, friends or neighbours who are typically unpaid (although we will include those in receipt of direct payments and allowances).
Reports outcomes valued by people with dementia or care partners	Studies should explore the views of people with dementia on outcomes valued for themselves (or their care partners) or the lived experience of dementia. Alternatively or additionally, studies could explore the views of care partners on outcomes valued for themselves (or the person whom they support) or the lived experience of caring for someone with dementia. Studies examining outcome measures will only be included where they report qualitative data on the views of people living with dementia or care partners to inform development.
Original qualitative data	We will include all designs providing data on the voices of people with dementia and care partners (interviews, focus groups, case studies, secondary analysis, auto-ethnographies and observation <i>if the latter includes field notes directly reporting the perspectives of people with dementia or care partners</i>). We will exclude (auto) biographies. Studies using survey data without open-ended questions or exploring responses to prepopulated lists of outcomes will be excluded. Studies using surveys with open-ended questions will be included if there is enough qualitative data to be reanalysed. Qualitative data from studies using mixed methods will be eligible for inclusion. Reviews, study protocols and editorials will not be eligible for inclusion. We will keep a record of relevant publications to check that related papers have been included where appropriate.
Published in the English language	Resources are not available to include studies published in languages other than English. Since excluding papers not written in English may introduce a language bias, we will follow the recommendations of the Joanna Briggs Institute to search inclusively and keep a record of the number of potentially relevant excluded studies by language.

text papers retrieved will be reviewed by two researchers. Ongoing meetings of the review team will discuss and resolve any disagreements regarding eligibility. If necessary, study authors will be contacted for further information; if a response is not received within 1 month, the article may be excluded if essential data are missing.

Data extraction and management

EndNote software will be used for data management and deduplication, in combination with Rayyan QCRI software⁴⁷ to facilitate the screening process.

NVivo V.12 software will be used to assist data extraction and analysis. Drawing on work by Houghton and Murphy,⁴⁸ each included paper will be assigned to a case and attributes used to record key information. In accordance with the thematic synthesis method, full results or findings sections will be extracted and stored within the NVivo software. Additional data extracted will include study methodology, country, setting, number and types of participants, whether the paper explicitly explored outcomes or focused on lived experience, date of data collection and variables relating to quality appraisal.

Assessment of quality of included studies

There is a lack of consensus about quality assessment in qualitative systematic reviews, and many different tools and techniques are available.⁴⁹ Following the approach to qualitative synthesis developed by Thomas and Harden,^{50 51} we intended to adapt quality appraisal criteria to our specific review. We examined several methods for quality assessment,^{46 50 52–56} mapping headings across tools and testing them on a small batch of papers; this identified some elements that were less relevant to our review (eg, they were not reported in the papers of interest) and others that were difficult to operationalise. Based on this exercise, we selected Croucher⁵⁶ as a base tool, due to its ease of operationalisation, coverage of the key quality issues relevant to our review and few superfluous items, and modified it accordingly. We will include items on the following:

- ▶ Appropriateness of the methods to ensure that the findings were rooted in the perspectives of participants.
- ▶ Adequacy of strategies to establish the validity of the findings.
- ▶ The quality of reporting.

Studies will not be excluded on the basis of quality, but quality appraisal will be used to assess confidence in the review findings.

Data synthesis and analysis

The findings or results sections of included papers will form the data for the synthesis. The three-stage thematic synthesis approach described will be followed: line-by-line coding, identification of descriptive themes and development of conceptual themes. We will also draw on the thematic approach described by Braun and Clarke⁵⁷ for the process of familiarisation with the data and generation of initial codes. Reported findings and interpretation will not be taken at face value but will be subject to a process of scrutiny and reconceptualisation, particularly those relating to lived experiences, as the extent to which outcomes are explicitly articulated will vary between papers. Lived experience data will be interpreted through an outcome 'lens', for example looking for terminology

that can be interpreted as expressing a desired outcome (eg, 'want', 'need' and 'wish') or identifying an element of postdiagnostic support that is missing; at this stage, our aim will be to stick closely to the terms used by participants and avoid imposing concepts on the data. Initial codes will be discussed in data workshops to produce a preliminary list of potential outcomes. This process will continue iteratively until the dataset has been analysed.

At each stage, emerging codes and concepts will be discussed in data workshops involving all available reviewers. Narrative summaries of each descriptive code will be produced by researchers and discussed in further data workshops to identify emerging conceptual themes. We will compare the outcomes identified by the following:

- ▶ People living with dementia for themselves.
- ▶ Care partners for people living with dementia.
- ▶ People living with dementia for their care partners.
- ▶ Care partners for themselves.

Assessment of confidence in the review findings

We will use the GRADE-CERQual ('Confidence in the Evidence from Reviews of Qualitative research') approach to reflexively assess confidence in the review findings.⁵⁸ This involves an assessment of each individual review finding in relation to the following four areas:

- ▶ Methodological limitations (the extent to which there are concerns about the design or conduct of the primary studies that contributed evidence to an individual review finding).
- ▶ Coherence (an assessment of how clear, well supported or compelling the fit is between the data from the primary studies and a review finding that synthesises the original data).
- ▶ Adequacy of data (an overall determination of the degree of richness and quantity of data supporting a review finding).
- ▶ Relevance (the extent to which the body of evidence from the primary studies supporting a review finding is applicable to the context, perspective or population).

Reflexivity about the context of knowledge production and the effect of the researchers is central to good qualitative research, including evidence synthesis.⁵⁹ Using the CERQual approach will enable us to be explicit about how and why judgements about individual review findings have been made and to check for consistency across and between different types of papers (outcomes and lived experience). Furthermore, examining each review finding in detail allows a more nuanced assessment than a global statement about the confidence in the findings. This information will be presented in a Summary of Qualitative Findings table.⁶⁰

Patient and public involvement

A mixed stakeholder involvement group, comprising people living with dementia, current and former care partners and professionals working with these groups, has informed the design of this review and will contribute to the interpretation of the review findings. The Dementia

Care Community (DCC) was established in 2018 to ensure stakeholder involvement is embedded throughout the conduct and dissemination of our research programme.

The DCC has shaped the design of this review in two ways: first, by highlighting that a wide range of outcomes need to be considered since their relative importance is determined by personal preferences, circumstances and point along the illness trajectory and, second, by emphasising the need to consider outcomes for care partners, as well as those for people living with dementia. The DCC will also contribute to identifying conclusions from the results of the review and identify appropriate dissemination routes for non-academic audiences.

Ethics and dissemination

Research ethics approval and consent to participate are not required for this review. We will draw on guidelines for the publication of qualitative synthesis in reporting the findings. The findings will be made accessible to health and care professionals, policy makers and decision-makers and the public. The results will be disseminated at regional, national and international conferences.

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Contributors Contributor LR is the guarantor of the review. CB, LR and AW conceived the initial study idea, and AW, CB and GB completed the preliminary work to inform its development. LB, CB, GB, LR and AW drafted the manuscript. All authors (LB, CB, GB, SB, JM, LR and AW) made substantial contributions to the design of the study, revised the manuscript critically for important intellectual content and approved the final manuscript.

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